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ABILHAND-Kids questionnaire: responsive to change or room for change?

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"ABILHAND-Kids questionnaire – responsive to change or room for change?"

Developed by Arnould et al[1] in 2004, the ABILHAND-Kids questionnaire is a Rasch-based measure of manual ability in children aged 6 to 15 years with cerebral palsy (CP). It was created to address the lack of appropriate instruments for measuring the ability of these children to use their hands in activities of daily living. The questionnaire measures parental perception of a child's *performance,* relying on parental recall within the preceding 3 months. Each item is scored on a 3-point scale (impossible, difficult, easy).

Bleyenheuft et al[2] have demonstrated that the ABILHAND-Kids questionnaire is responsive to change. They used the measure with an exclusively unilateral spastic cerebral palsy (USCP) cohort, as did we[3]. The questionnaire is validated for children with all types of CP between the ages of 6 and 15 years, and when used only with children with USCP the item hierarchies may be altered[4]. Whilst item hierarchy was found to be invariant across CP subtypes in the original study (undertaken in French), the British and American versions of the questionnaire have not been Rasch analysed following translation from the original French version.

In a UK setting we found that some items within the ABILHAND-Kids questionnaire were ambiguous[4]. Parents are instructed to answer "irrespective of the limb used to do the activity". How might parents answer regarding "switching on a bedside lamp" or "taking a coin out of a pocket"? Both tasks are achievable unimanually, but performance in those with USCP will depend very much on the limb used, and for that matter, on the location of the pocket or lamp in relation to that limb. Parental replies may reflect how they *think* they are expected to answer.

As the authors point out, increased consistency of response is likely if the same parent completes the questionnaire at each visit and if parents are given the opportunity to ask clarifying questions. For practical reasons it can be difficult, particularly in a clinical setting, to ensure the former requirement. Even with the same parent responding each time, reliance on parental recall may be problematic for items which are rarely observed. Guessing or omitting responses may adversely affect the reliability of this measure – but requiring the child to perform the task at the time of questionnaire completion changes the nature of the assessment. Furthermore, there is potential ambiguity in terms of the specific items being considered: for example, the difficulty of unwrapping a chocolate bar will depend on the nature of the wrapping of that specific bar. Similarly, toothpaste tubes with flip caps versus screw tops present quite different levels of challenge in USCP.

The ABILHAND-Kids questionnaire is useful in a clinical setting as it is quick to complete. By having a paper-based format, it avoids the information governance issues around parental login and data-sharing that arise with parental completion of online measures such as the Children's Hand-use Experience Questionnaire (CHEQ)[5]. The questionnaire could be refined through the use of additional instructions and illustrations (for example images of chocolate bars and toothpaste tubes to specify design issues affecting performance). Addition of space for annotations by parents could provide clarification at the analysis stage or when comparing results from two questionnaires, though it could also complicate analysis. Bleyenheuft et al[2] identified that the questionnaire was less responsive in

adolescents and suggest that a new tool may be required for this age group. Further development of this tool for different subgroups of CP taking into account the suggestions above could improve the robustness of this measure.

Developing and validating assessment tools is an extremely challenging process. We are fortunate that in the field of cerebral palsy, considerable efforts are being made to capture aspects of hand function (both performance and capacity-based; unimanual and bimanual) with well-validated tools. No single measure can be perfect, but through combinations of assessments we can now accurately evaluate outcomes from well-designed interventional studies.

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